

Summary: The DIPG Awareness Resolution in the US House of Representatives

H. Res. 404

“Expressing support for the designation of the 17th day in May as “DIPG Awareness Day” to raise awareness and encourage research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.”

General Description

Despite its consistent death toll as the leading cause of disease-related childhood mortality in the US, childhood brain cancer, of which DIPG (diffuse intrinsic pontine glioma) is the 2nd most common type and the deadliest, has seen no significant change in the standard treatment protocol nor prognosis of the worst variety since Neil Armstrong’s daughter died of it in 1962. DIPG exemplifies in a powerful way the challenges in treating pediatric cancer and the daily tragedies which ensue from the general lack of solutions our medical research industry has for deadly pediatric disease. As such the resolution is meant to increase public awareness for childhood brain cancer, DIPG, and expedite research funding into cures for pediatric cancer in general.

The DIPG Awareness Resolution was first introduced to the US House of Representatives (114th Congress) in 2016 requiring only a House vote to pass; it is not a law. It is apolitical with no direct funding authorization. It does, however, suggest that for any given cancer type, that the years of human life lost associated with it as well as the mortality rate be given elevated consideration in the research grant process with public and private funding sources. It shines a national spotlight on an issue of human suffering which has remained in obscurity for decades. To date, a similar resolution has been introduced thrice in the Senate, passing with unanimous consent in 2019, 2020, and 2021.

History

The DIPG Awareness Resolution has its origins in the 2014 California Legislature, with the first state resolution designating the last week in May, Brain Tumor Awareness Month, as “DIPG Awareness Week.” It was introduced by CA State Assemblyman Scott Wilk, who is the current State Senator. Steve Knight, CA-State Senator 2012- 2014, was elected Congressman in Nov. 2014 for the 25th District of California. In September of 2015, his constituent Janet Demeter with the foundation Jack’s Angels, instrumental to the 2014 California Resolution, worked with his office to introduce the first DIPG Awareness Resolution to the 114th US Congress on January 13, 2016, also designating the final week of May. The co-lead for H. Res. 586 was Debbie Dingell (D-MI-12), in honor of Chad Carr in Ann Harbor, MI. Exclusive to the first introduction, the original resolution was referred to as “Chad and Jack’s DIPG Awareness Resolution” honoring Chad Carr and Jack Demeter of Agua Dulce, CA, respectively.

Having formed upon the death of Michael Mosier on May 17 of 2015, the Michael Mosier Defeat DIPG Foundation in Bethesda, MD began a campaign in 2016 to encourage as many states as possible to commemorate DIPG children on the 17th day of May. Having followed Michael’s journey, Janet Demeter worked with her Congressman to change the national Resolution, which was reintroduced in January of 2017 to the 115th Congress as H. Res. 69, to designate May 17 as part of its language for greater solidarity and awareness of the project in the childhood cancer community and to help ensure its success. To date, over 34 states have recognized DIPG Awareness Day, May 17th, either by gubernatorial proclamation or by the state legislature.

Subsequently H. Res. 69 finished the 115th Congress with over 50 cosponsors, and then in the 116th Congress, H. Res. 114, the resolution gained the support of nearly half the House with 215 signatures recorded, and again

without regards from House Leadership for a floor vote. On May 17, 2021 the resolution was introduced for a fourth time, with Congresswoman Debbie Dingell (D-MI-12), and Congressman David Joyce (R-OH-14) leading in the 117th Congress. DIPG Advocacy Group is hopeful to achieve a super-majority of support for the resolution during the 117th Congress, ever hopeful for House Leadership to consider scheduling it for a vote on or before May 17, 2022.

House Rules

It is important to note that “commemorative” resolutions were restricted in the 1990’s due to excessive overuse at the time, taking valuable floor-time away from matters of import to the People’s House of Representatives. However, an exception protocol was added to this rule in 2016 for matters of bereavement and/or requiring certain remedial action, to make way for the Patriot’s Day Resolution. DIPG Advocacy Group insists that children suffering and dying from cancer mainly due to lack of investment into cures, exemplified by the horrific yet not uncommon experience of DIPG, indeed ought to merit the simple consideration of House Leadership for time on the floor of the People’s House. Advocates maintain that, as brain cancer leads in childhood cancer incidence and childhood cancer deaths in America, this rule from another time, place, and circumstance ought to be reviewed for relevance, and given consideration with the exception protocol, “A resolution of bereavement, or condemnation, or which calls on others to take a particular action, is eligible to be scheduled for consideration.” *

***In the Senate: DIPG Pediatric Brain Cancer Awareness Resolution**

The resistance to consideration for the DIPG Awareness Resolution in the House to be scheduled for a vote inspired the quest for a Senate Resolution. Upon the formation of the DIPG Advocacy Group in the fall of 2017, founders Janet Demeter, Elizabeth Psar (Knoxville, TN) and Paul Miller (Littleton, CO) began to pursue a Senate resolution with advocates Wendy Fachon (Greenwich, RI) and Kirsten Finley (Ormond Beach, FL), as Senators Rubio (FL) and Reed (RI) were the original leading sponsors for all three resolutions. The process being much more favorable to success in the Senate, the 2019, 2020, and 2021 resolutions passed with unanimous consent, with similar though more abbreviated language, and designating May 17th as National DIPG/Pediatric Brain Cancer Awareness Day. The process involves a unanimous “hotlined” vote and must be repeated yearly, as the commemorative language of Senate Resolutions recognize one specific date or period of time only. The House Resolution, were it to pass, would recognize May 17th as DIPG Awareness Day in perpetuity.

DIPG Advocacy Group will pursue success for the House Resolution to attract a cure more quickly and to help save lives today with greater knowledge and education of pediatric brain cancer, asserting that our Representatives in the House are our closest representation in the Federal Government, and federal recognition matters. For the thousands of children who never have had the chance to live, and equally for their devastated families and communities, finding viable treatments for this torturous death sentence which is DIPG and the children who continue to suffer unseen, would veritably be a “Moonshot for kids” fulfilled. #Moonshot4Kids.

*<https://www.majorityleader.gov/content/117th-congress-legislative-protocols>

DIPG Advocacy Group Letter to Congress with Resolution Text and Endorsements: bit.ly/HRes404-921